

Anaphylaxis in adulthood: exploring the psychological experience and patient-centred care

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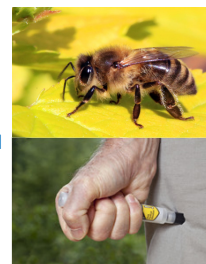


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Background and Aims

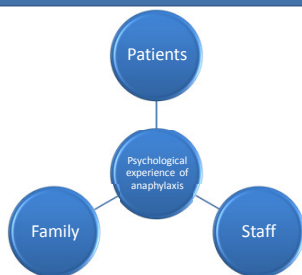
- Anaphylaxis is a serious, rapid allergic reaction which may cause death (Sampson et al., 2006). Increasingly prevalent, anaphylaxis causes 20 deaths a year in the UK (Pumphrey, 2000). Food, medication and insect stings are common causes of anaphylaxis, however in 30-60% of referrals, anaphylaxis is idiopathic (no identifiable trigger) (Lieberman, 2014).
- Research on the psychological impact of this life threatening condition is limited and has generally focused on children and adolescents with identifiable trigger anaphylaxis (e.g. Akeson, Worth & Sheikh, 2007).
- Understanding the psychological experience of anaphylaxis in adulthood will enable the identification of what is needed by patients, family members and staff to better guide and support services and, ultimately, improve patient-centred care.



Aims:

- To explore with patients, family members, friends and staff the psychological impact of anaphylaxis first experienced in adulthood
- To outline how the psychological needs of adults with anaphylaxis are currently addressed within Allergy services

Method



- A qualitative, multi-perspective interview design was utilised in which patients, family members and staff were recruited via a local Allergy Clinic.
- Semi-structured interviews around the experience of anaphylaxis and its management were conducted with adult patients (n = 7), family members (n = 3) and nursing staff (n = 2). Triggers of anaphylaxis for participants interviewed included bees, wasps, codeine, exercise & wheat, and idiopathic (no identifiable trigger).
- Interpretative Phenomenological Analysis (IPA) was utilised as the method of analysis (Smith, Flowers & Larkin, 2009) as this approach is particularly useful for providing in-depth understandings of the meaning and experience of illness.

Results

An unknown, uncertain experience:

"To tell you the truth, the thought went through my mind, I thought, 'I'm gonna die here and I haven't said goodbye to my kids,' because it was just so frightening for it just to happen just like that and it was really, really frightening" (Patient 6)

The importance of control:

"I suppose, with anything that is perceived as a threat, it's how far you can control your exposure to that threat, isn't it?" (Staff member 1)

Responsibility but no control – the impact on others:

"The feeling of helplessness that you have when you are the family member in so far as the allergen is, is there and you just have to, kind of, avoid it, which is easier said than done sometimes. And particularly if your family member doesn't take it very seriously... you can feel powerless to protect them." (Family 1)

Two superordinate themes were identified:
Controllability and
Conflict

Rejecting illness identity:

"My life has been very much an independent, quite an adventurous existence, and being limited by the proximity, being close to an injection that you probably won't use just feels a little bit foreign to me" (Patient 1)

Running in slow motion:

"To have to wait 12 months to get to the allergy clinic to find out any result is a long time, and it's very, very worrying, and that could have a big impact on people and their families because you feel like your life's on hold because you need to know why it happened." (Patient 6)

Minimisation of threat :

"You've been through it and successfully survived, so the prospect of imminent death recedes a little bit." (Patient 1)

Discussion and Implications for Practice

Discussion:

- Patients, family members and staff highlighted the important role of controllability and conflict in the psychological experience of anaphylaxis and its management.
- Findings are consistent with self-regulatory theory (Leventhal, 1979) which suggests people form cognitive and emotional representations of a health threat which reciprocally influence coping.
- Findings are also supported by research on young people and parents which highlighted a blasé attitude in patients, heightened anxiety in family members and multiple barriers to effective self-management (Akeson, Worth & Sheikh, 2007).

Implications for Practice:

- Allergy services should ensure patients receive timely and appropriate information on the diagnosis and treatment process to avoid further compounding patient and family uncertainty.
- Screening for psychological distress and signposting to sources of support should be included in the care pathway.
- Epi-pen training should acknowledge and respond to the complex psychological factors that lead to non-adherence.
- Information, training and support should ideally be offered to family members.

References

Akeson, N., Worth, A., & Sheikh, A. (2007). The psychosocial impact of anaphylaxis on young people and their parents. *Clinical & Experimental Allergy*, 37(8), 1213-1213. Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. *Contributions to Medical Psychology*, 2, 7-30. Lieberman, P. L. (2014). Idiopathic anaphylaxis. *Allergy and Asthma Proceedings*, 35(1), 17-23. Pumphrey, R.S. (2000). Lessons for management of anaphylaxis from a study of fatal reactions. *Clinical and Experimental Allergy*, 30(8), 1144-50. Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage